



Research and Statistics Note

No. 2012-04

October 2012

Changes in Diagnostic Codes at Age 18

*by Jeffrey Hemmeter**

Introduction

Each year, as tens of thousands of child Supplemental Security Income (SSI) recipients reach age 18, the Social Security Administration (SSA) redetermines their medical eligibility according to adult disability standards. Child participation in the SSI program has grown substantially in recent years, and youth with mental impairments make up an increasing proportion of the program population (SSA 2012a). The growth in the proportion of children with mental impairments among SSI recipients has led to concern among some individuals that too many youth receive SSI.¹ As the SSI youth population increases and transitions into adulthood, the potential for long-term program participation increases as well.² In addition, some have argued that certain mental impairments, such as speech and language delays, are more subjective or time-limited (Burkhauser and Daly 2011), requiring more vigilant oversight by SSA.³ Although SSA conducts continuing disability reviews (CDRs) on SSI recipients, limited funding and resources have led to fewer CDRs being conducted for child SSI recipients than the law requires (GAO 2011). For many child SSI recipients, the age-18 redetermination is the first time their disability is reviewed during their tenure in the program.

The concerns about the number and program tenure of children with mental impairments may be justified if a higher proportion of those children are removed from the program or reclassified with other diagnoses during their age-18 redeterminations. However, the statistics in this note show that, relative

* Jeffrey Hemmeter is with the Office of Program Development and Research, Office of Retirement and Disability Policy, Social Security Administration.

Acknowledgments: The author thanks Paul Davies, Jim Twist, Scott Muller, Shelley Stegman, Susan Kalasunas, M.J. Pencarski, Michael Stephens, Mary McKay, Joseph Cholewczynski, and David Weaver for comments on early drafts of this note, and Bob Somers for providing the data.

The findings and conclusions presented in this note are those of the author and do not necessarily represent the views of the Social Security Administration.

¹ For a variety of viewpoints on the SSI program, see recent Congressional hearing testimony at <http://www.waysandmeans.house.gov/calendar/eventsingle.aspx?EventID=265128>.

² With the Youth Transition Demonstration project, SSA is testing interventions that may help reduce long-term SSI dependency (see <http://www.socialsecurity.gov/disabilityresearch/youth.htm>).

³ Note, however, that the Social Security Act does not limit the types of mental disabilities that can qualify a claimant for SSI payments. Secular trends in the diagnosis of certain mental disabilities, such as the recent increase in autism spectrum disorders and decline in intellectual disability, will naturally be reflected in the SSI program.

to youth with mental disabilities, those with many nonmental disabilities experience similar or higher rates of both program removal and continuation with a different diagnosis at the age-18 redetermination.

SSA standards for CDRs differ from those for age-18 redetermination: CDRs generally require medical improvement since the last favorable decision for a cessation decision, and age-18 redeterminations are treated as a new medical decision based on adult standards (discussed in the next section). Thus, cessations and diagnostic changes at age 18 do not necessarily imply incorrect initial allowances to the program. The outcomes could equally indicate a system that accurately addresses the different needs of children and adults. Nonetheless, it is important to understand how the disabilities of youth who undergo an age-18 redetermination are reclassified. This note provides statistics on those reclassifications, focusing on childhood mental impairments, thus affording a more complete picture of the transition experiences of SSI youth.

Selected Abbreviations	
CDR	Continuing disability review
SSA	Social Security Administration
SSI	Supplemental Security Income

The Age-18 Redetermination

SSA redetermines the medical eligibility of each child SSI recipient when he or she attains age 18.⁴ To remain eligible, the youth must meet the adult standards of disability, which may be more restrictive than the standards for children (although SSA improved the equivalency of disability decision processes for adults and children in the wake of the 1990 *Sullivan v. Zebley* decision).⁵ Additionally, for those who do not have a listing-level disability, a child's disability must result in "marked and severe functional limitations," whereas an adult's disability must result in the inability to perform substantial gainful activity.⁶

The outcome of roughly two-thirds of these redeterminations, after appeals, is program continuation (SSA 2012a). Youth diagnosed with mental impairments other than "intellectual disabilities or schizophrenia" and "psychoses and other neuroses" are among the most likely to receive an initial cessation and the least likely to appeal or return to the program (Hemmeter and Gilby 2009). Roughly 10 percent

⁴ SSA maintains an official listing of impairments that identifies disabilities severe enough to qualify an individual for SSI. If an individual's disability or combination of disabilities does not meet the listing's criteria, he or she may still be eligible for SSI based on other criteria measuring the overall effect of the disability. There are 133 adult and 93 childhood impairment listings (including multiple diagnostic categories within a listing). Under mental disorders, there are 11 adult and 18 childhood listings. Because individuals can receive the impairment code most closely matching a given listing-level diagnosis even if they do not meet the listing criteria, it is not possible to distinguish those who met the listing criteria from those who did not in the data available for this study. See SSA (2012b) for more information on diagnosis coding.

⁵ In *Sullivan v. Zebley*, the US Supreme Court found that SSA's existing policy of allowing children onto SSI only if they had a listing-level disability differed from SSA's disability determination policy for adults, which included an extra step to determine if adults had a disability of equal severity to the listing criteria. Thus, SSA was determined not to be in compliance with the Social Security Act under which children are considered disabled if they have an impairment of *comparable severity* to one that would disable an adult. As a result of this decision, SSA implemented an individual functional assessment step for children, enabling more youth to medically qualify for SSI. However, comparable functional limitations are difficult to determine given the different functions children and adults are expected to perform. Acknowledging these differences, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 redefined childhood disability as requiring "marked and severe functional limitations" and required all youth on SSI to receive an eligibility redetermination at age 18.

⁶ Although the SSI child and adult programs share common income and resource limits, parental income is treated differently for children and adults, with youth aged 18 or older having less parental income deemed to them than children younger than 18. Additionally, some student earnings are not counted toward the income limit before age 22.

of youth whose eligibility ceases at age 18 successfully reapply for SSI payments as an adult within 4 years. Readers interested in other aspects of the age-18 redetermination are referred to Rogowski and others (2002), Hemmeter and Gilby (2009), and Hemmeter, Kauff, and Wittenburg (2009).

Data and Methods

The data for this study come from the CDR Waterfall File, provided by SSA's Office of Quality Performance's Office of Continuing Disability Review Support in August 2010. That file contains records for all centrally initiated full medical reviews, including age-18 redeterminations. I limit the analysis to redeterminations released in calendar years 2005 through 2009. The file contains 314,620 age-18 redeterminations with a final decision reached during that period; the analysis excludes pending appeals.⁷

This analysis compares the primary impairment code that was assigned prior to the redetermination with the code assigned at the last redetermination decision either to continue or cease SSI receipt.⁸ Although individuals may have several disabilities, SSA files generally record only two diagnosis codes (primary and secondary). Typically, the primary diagnosis code identifies the main disabling condition on which the decision is based, but different examiners may disagree on which condition is the main one or may view multiple conditions equally. Additionally, once SSA receives enough evidence to cease or continue SSI eligibility, the review process usually ends, which may be before evidence is presented for *all* alleged disabilities. Thus, the information in the primary diagnosis fields of the data does not provide a complete picture of the disability (or disabilities) for which the individual receives SSI. The extract of the CDR Waterfall File includes the primary diagnosis codes from before the age-18 redetermination,⁹ the initial redetermination decision, and each decision during the appeal process.¹⁰ SSA statistical publications (for example, the *SSI Annual Statistical Report*) uniformly group the codes into diagnostic categories.

The redetermination code may differ from the child disability code for several reasons. For instance, some child disabilities (such as learning disabilities) are not allowable under adult program rules, resulting in either a cessation with a code of no impairment or a continuation under a different disability. As noted earlier, this occurrence implies neither a new disability nor an error in the original code; this "new" disability may have always been present, albeit not as severe as the disability alleged during the last favorable decision (most likely the initial award) or as easy to establish. The "new" disability may also have been listed as the child recipient's secondary code (which is not recorded on the CDR Waterfall File extract used in this analysis), or evidence of it may not have been gathered because another eligible condition was present. However, because the primary diagnosis code on record is typically the easiest and clearest to establish, disabilities that may be easier to establish as a child than as an adult may be relegated to the secondary code or not recorded at all after the adult redetermination.

⁷The file includes 26,142 pending cases, representing 0.72 percent of the 2005 redeterminations and increasing shares in successive years, up to 17.1 percent of the 2009 redeterminations. Appendix Table A-1 shows redetermination outcomes by year of release.

⁸See Panis and others (2000) for a listing of diagnosis codes and groupings. I actually use an updated diagnosis list, but Panis and others explain how these codes are grouped and used in SSA files.

⁹The pre-redetermination diagnosis code is an amalgam of codes from different sources to help fill in blank codes. There is no associated secondary diagnosis code for the pre-redetermination period in the available extract of the data.

¹⁰The file also contains the secondary diagnosis codes for decisions made by the state Disability Determination Services at the initial redetermination decision level.

Which Diagnostic Groups Retain the Same Primary Diagnosis Code or Diagnostic Group?

Table 1 presents the percentages of age-18 redeterminations from 2005 through 2009 in which the child and redetermination primary diagnosis codes are the same, the primary diagnostic groups are the same but the diagnosis codes differ, the primary diagnostic groups are the same, and the primary diagnostic groups differ. Overall, 57 percent of child SSI recipients who continue in the program as adults retain their primary diagnosis code after redetermination; only 30 percent of those whose redeterminations cease SSI retain their primary diagnosis code. This is unsurprising because SSA can also find insufficient evidence to establish an impairment code, or “no disability,” for the ceased group. However, 70 percent of continued recipients and 60 percent of ceased recipients retain the same diagnostic *group*, and only 5 percent of ceased recipients have insufficient medical evidence to establish an impairment code (not shown in Table 1), suggesting the “no disability” finding does not drive the change in codes for ceased recipients. Thirteen percent of continued recipients and 30 percent of ceased recipients retain the same diagnostic group but have different diagnosis codes.

Table 1 also shows the percentages of child recipients in each diagnostic group ceased and continued during their age-18 redetermination. The diagnostic groups with the highest continuation rates are congenital anomalies (90 percent) followed by diseases of the nervous system and sense organs (88 percent). Disabilities in these two categories are generally more static than the others. Just under one-half of recipients in the “other mental disorders” group (47 percent) are continued, as are those with neoplasms (47 percent) and digestive system diseases (49 percent). Recipients with respiratory system diseases have the lowest continuation rate (25 percent). Several groups are also in the 50 to 60 percent continuation range: endocrine, nutritional, and metabolic diseases (53 percent), skin and subcutaneous tissue diseases (56 percent), and musculoskeletal system and connective tissue diseases (59 percent). Thus, although youth with “other mental disorders” are among the least likely to continue receiving SSI as adults, other diagnostic groups have similar continuation rates.

Continued Recipients

Among those who continued receiving SSI after the age-18 redetermination, individuals first diagnosed with blood and blood-forming organs diseases (80 percent) and intellectual disabilities (82 percent) are most likely to retain their primary diagnosis code. In the following groups, over 50 percent also retain their primary impairment code: infectious and parasitic disease; endocrine, nutritional, and metabolic diseases; schizophrenia, psychoses, and other neuroses; nervous system and sense organs diseases; genitourinary system diseases; and congenital anomalies. The continued groups least likely to retain their primary diagnosis code include those coded as youths with “unknown” (5 percent) or “other” (8 percent) disabilities.

Recipients whose primary diagnosis codes change upon redetermination may still remain in the same diagnostic group. As a result, majorities of continued recipients in 14 of the 18 diagnostic groups do not change groups. For example, although only 28 percent of youth in the “other mental disorders” group retain that diagnosis code after redetermination continues their SSI, another 34 percent receive a different diagnosis code within that group. Thus, 62 percent remain in the “other mental disorders” group.

Ceased Recipients

SSI-ceased individuals with respiratory system diseases (63 percent) and blood and blood-forming organs diseases (64 percent) are the most likely to retain their primary diagnosis code after the age-18 redetermination. Youth with unknown diseases (8 percent) or infectious and parasitic diseases

Table 1.
SSI age-18 redetermination primary diagnoses and diagnostic groups, by eligibility outcome and diagnostic group to which recipients were designated as children, 2005–2009

Child diagnostic group and redetermination eligibility outcome	Number	Percentage distribution	Percentage of redetermination (adult) diagnoses that—		Percentage of redetermination (adult) diagnostic groups that—	
			Match child diagnosis	Match child diagnostic group, but not child diagnosis	Match child diagnostic group	Differ from child diagnostic group
Total	314,620	100.0	46.9	19.4	66.2	33.8
Ceased	117,816	37.4	30.2	29.5	59.7	40.4
Continued	196,804	62.6	56.9	13.3	70.1	29.9
Congenital anomalies						
Ceased	734	10.2	42.2	2.0	44.3	55.7
Continued	6,430	89.8	59.1	1.7	60.8	39.2
Endocrine, nutritional, and metabolic diseases						
Ceased	887	47.1	54.3	4.1	58.4	41.6
Continued	998	52.9	56.5	3.6	60.1	39.9
Infectious and parasitic diseases						
Ceased	15	25.0	6.7	0.0	6.7	93.3
Continued	45	75.0	57.8	2.2	60.0	40.0
Injuries						
Ceased	462	21.1	32.5	9.7	42.2	57.8
Continued	1,726	78.9	45.9	12.0	57.9	42.1
Mental disorders						
Intellectual disability						
Ceased	28,708	26.3	30.1	...	30.1	70.0
Continued	80,395	73.7	81.7	...	81.7	18.3
Schizophrenia, psychoses, and other neuroses						
Ceased	1,282	29.6	18.6	...	18.6	81.4
Continued	3,047	70.4	57.2	...	57.2	42.8
Other mental disorders						
Ceased	72,240	52.6	27.8	46.3	74.0	26.0
Continued	65,017	47.4	28.1	34.1	62.3	37.8
Neoplasms						
Ceased	1,084	53.2	50.7	9.3	60.1	39.9
Continued	954	46.8	40.2	14.7	54.8	45.2
Diseases of the—						
Blood and blood-forming organs						
Ceased	862	24.5	64.0	11.7	75.8	24.3
Continued	2,661	75.5	79.8	10.1	89.9	10.2
Circulatory system						
Ceased	313	34.9	33.9	14.7	48.6	51.4
Continued	585	65.1	34.5	6.2	40.7	59.3
Digestive system						
Ceased	354	51.4	41.5	16.1	57.6	42.4
Continued	335	48.6	38.2	15.8	54.0	46.0

(Continued)

Table 1.
SSI age-18 redetermination primary diagnoses and diagnostic groups, by eligibility outcome and diagnostic group to which recipients were designated as children, 2005–2009—Continued

Child diagnostic group and redetermination eligibility outcome	Number	Percentage distribution	Percentage of redetermination (adult) diagnoses that—		Percentage of redetermination (adult) diagnostic groups that—	
			Match child diagnosis	Match child diagnostic group, but not child diagnosis	Match child diagnostic group	Differ from child diagnostic group
Diseases of the—						
Genitourinary system						
Ceased	412	35.0	57.3	9.2	66.5	33.5
Continued	766	65.0	64.0	11.6	75.6	24.4
Musculoskeletal system and connective tissue						
Ceased	1,240	41.0	42.8	16.9	59.7	40.3
Continued	1,788	59.0	36.9	18.6	55.5	44.5
Nervous system and sense						
Ceased	3,399	12.5	50.3	8.9	59.2	40.8
Continued	23,888	87.5	67.8	10.5	78.4	21.6
Respiratory system						
Ceased	2,388	75.5	63.4	2.7	66.1	33.9
Continued	775	24.5	37.0	4.0	41.0	59.0
Skin and subcutaneous tissue						
Ceased	104	43.7	32.7	10.6	43.3	56.7
Continued	134	56.3	44.8	19.4	64.2	35.8
Other						
Ceased	1,392	33.4	9.6	0.2	9.8	90.2
Continued	2,770	66.6	7.8	1.1	8.8	91.2
Unknown						
Ceased	1,940	30.2	7.9	16.0	23.9	76.1
Continued	4,490	69.8	4.7	1.6	6.3	93.7

SOURCE: Author's calculations using SSA Office of Quality Performance CDR Waterfall File.

NOTES: Diagnoses are based on primary RPDY (Recoded Primary Impairment) codes. Sample excludes redeterminations with an appeal decision pending. Diagnostic groups conform to those used in SSA statistical publications.

Rounded components of percentage distributions do not necessarily sum to 100.

... = not applicable (these diagnostic groups consist of a single diagnosis code).

(7 percent) are the least likely ceased recipients to retain their original primary diagnosis code. Over 50 percent of ceased cases in the following groups retain their primary diagnosis code after the redetermination: neoplasms; endocrine, nutritional, and metabolic diseases; blood and blood-forming organs diseases; nervous system and sense organs diseases; respiratory system diseases; and genitourinary system diseases.

As with continued recipients, many ceased recipients change diagnosis code but not diagnostic group. This is most common in the “other mental disorders” group, with 46 percent of ceased recipients changing primary diagnosis code but not diagnostic group. In all, though, majorities of ceased recipients retain their primary diagnostic group in 9 of the 18 groups.

A Closer Look at Mental Impairments

As noted earlier, there is particular interest in the redetermination outcomes of youth with mental impairments. As reported in Table 1, among continued recipients, 82 percent with intellectual disabilities, 57 percent with schizophrenia, paranoia, and other psychoses, and 28 percent with other mental disorders as youth retain their primary diagnostic code after the age-18 redetermination. For recipients (both continued and ceased) with other mental disorders as youth, a change in diagnosis code within the diagnostic group is more common than retaining the diagnosis code after redetermination. Among ceased recipients, only 30 percent with intellectual disabilities and 19 percent with schizophrenia, paranoia, and other psychoses as youths retain their code/group.¹¹ This outcome raises the question of what, if any, redetermination diagnosis is recorded for these individuals. Table 2 presents the mental disorder primary diagnosis codes for child SSI recipients before and after the age-18 redetermination, by whether SSI receipt ceased or continued.¹² The diagnosis codes in Table 2 reflect impairment descriptions used in the SSA listings; the accompanying box shows how the listings correspond with the primary impairment codes and the diagnostic groups used in SSA statistical publications.

Recall from Table 1 that the “other mental disorders” group had an overall continuation rate of 47 percent. Within that group, Table 2 shows that diagnoses with higher rates of continuation include autistic disorders and other pervasive development disorders (92 percent), organic mental disorders (62 percent), affective disorders (49 percent), anxiety related disorders (53 percent), somatoform disorders (49 percent), eating and tic disorders (52 percent), and developmental and emotional disorders of newborn and younger infants (59 percent). Similarly, diagnoses with lower rates of continuation include personality disorders (43 percent), conduct disorders (35 percent), oppositional/defiant disorders (36 percent), attention deficit hyperactivity disorder (38 percent), learning disorders (41 percent), and borderline intellectual functioning (42 percent).

Within the “other mental disorder” group, low percentages of recipients retain their primary diagnosis code after the age-18 redetermination. The only groups in which more than 50 percent of continued recipients retain their original diagnosis are autistic disorders and other pervasive development disorders (63 percent) and affective disorders (57 percent). In all other diagnosis codes for continued recipients, and in all codes for ceased cases, less than half of individuals retain their primary diagnostic code after redetermination.

For many continued recipients whose primary diagnosis codes change at redetermination, the new code identifies an intellectual disability. For example, among continued recipients, intellectual disability is the primary redetermination diagnosis for 48 percent of those whose youth diagnosis was developmental and emotional disorder of newborn and younger infants, 51 percent who had speech and language delays, 50 percent who had learning disorders, and 46 percent who had borderline intellectual functioning. Overall, almost 30 percent of continued recipients in the “other mental disorders” diagnostic group as youth change to a diagnosis of intellectual disability at redetermination (not shown).

It may seem surprising that intellectual disability is not the primary childhood impairment for so many of these youth, given a basis for diagnosis that is more objective than those of other mental impairments.

¹¹ These diagnostic groups consist of a single diagnosis code.

¹² Table 2 only reports results if more than 4.9 percent of individuals fall into a given diagnosis code. Smaller percentages are accounted for in the “other” column.

Table 2.
Primary disability code transitions of children with mental impairments after the age-18 redetermination, 2005–2009

Child SSI recipient's primary impairment ^a	Redetermination outcome		Percentage diagnosed with a redetermination impairment of—					
	Number	Percentage distribution	Organic mental disorders (chronic brain syndrome)	Schizophrenic, paranoid, and other functional psychotic disorders	Affective disorders	Autistic disorders and other pervasive development disorders	Anxiety related disorders	Personality disorders
Organic mental disorders (chronic brain syndrome)								
Ceased	2,707	38.1	28.1	d	8.6	d	d	d
Continued	4,397	61.9	30.6	d	6.2	5.5	d	d
Affective disorders								
Ceased	12,092	51.1	7.4	d	47.3	d	d	d
Continued	11,579	48.9	6.9	6.9	57.1	d	d	d
Autistic disorders and other pervasive development disorders								
Ceased	809	7.6	11.9	d	7.5	31.4	d	d
Continued	9,894	92.4	d	d	d	62.7	d	d
Anxiety related disorders								
Ceased	1,935	46.9	7.5	d	27.2	d	19.4	d
Continued	2,187	53.1	7.7	d	29.6	d	26.7	d
Personality disorders								
Ceased	1,671	57.1	10.7	d	22.6	d	d	15.4
Continued	1,258	42.9	10.1	5.3	29.9	d	d	17.6
Somatoform disorders								
Ceased	35	50.7	5.7	d	11.4	d	d	d
Continued	34	49.3	5.9	d	11.8	8.8	d	5.9
Eating and tic disorder								
Ceased	85	47.8	14.1	d	22.4	d	5.9	d
Continued	93	52.2	22.6	d	24.7	5.4	8.6	d
Conduct disorder								
Ceased	2,755	65.0	10.7	d	19.1	d	d	5.3
Continued	1,484	35.0	11.1	6.9	27.1	d	d	7.9
Oppositional/defiant disorder								
Ceased	3,910	63.8	11.9	d	18.4	d	d	6.1
Continued	2,217	36.2	11.3	d	25.3	d	d	7.9
Attention deficit hyperactivity disorder								
Ceased	25,642	61.9	15.9	d	12.7	d	d	d
Continued	15,759	38.1	15.6	d	20.4	d	d	d
Developmental and emotional disorder of newborn and younger infants								
Ceased	392	41.2	25.0	d	9.2	d	d	d
Continued	560	58.8	9.3	d	5.5	13.9	d	d
Learning disorder								
Ceased	9,514	59.5	15.9	d	6.4	d	d	d
Continued	6,488	40.5	12.5	d	8.5	d	d	d
Speech and language delays								
Ceased	4,527	49.7	16.2	d	d	d	d	d
Continued	4,578	50.3	9.8	d	d	5.7	d	d
Borderline intellectual functioning								
Ceased	6,164	57.9	15.3	d	6.0	d	d	d
Continued	4,485	42.1	10.8	d	8.6	d	d	d
Schizophrenic, paranoid, and other functional psychotic disorders								
Ceased	1,282	29.6	6.9	18.6	26.6	d	d	d
Continued	3,047	70.4	d	57.2	18.7	d	d	d
Mental retardation ^b								
Ceased	28,708	26.3	11.2	d	d	d	d	d
Continued	80,395	73.7	d	d	d	d	d	d

(Continued)

Table 2.
Primary disability code transitions of children with mental impairments after the age-18 redetermination, 2005–2009—Continued

Child SSI recipient's primary impairment ^a	Percentage diagnosed with a redetermination impairment of—							
	Somatoform disorders	Eating and tic disorder	Conduct disorder	Oppositional/defiant disorder	Attention deficit hyperactivity disorder	Learning disorder	Speech and language delays	Mental retardation ^b
Organic mental disorders (chronic brain syndrome)								
Ceased	d	d	d	d	5.8	8.6	d	5.6
Continued	d	d	d	d	d	d	d	37.8
Affective disorders								
Ceased	d	d	d	d	6.0	d	d	d
Continued	d	d	d	d	d	d	d	11.6
Autistic disorders and other pervasive development disorders								
Ceased	d	d	d	d	6.7	5.4	d	d
Continued	d	d	d	d	d	d	d	26.2
Anxiety related disorders								
Ceased	d	d	d	d	5.3	d	d	d
Continued	d	d	d	d	d	d	d	12.8
Personality disorders								
Ceased	d	d	d	d	8.3	d	d	d
Continued	d	d	d	d	d	d	d	17.8
Somatoform disorders								
Ceased	14.3	d	d	d	5.7	5.7	d	5.7
Continued	32.4	d	d	d	d	d	d	23.5
Eating and tic disorder								
Ceased	d	15.3	d	d	d	d	d	d
Continued	d	d	d	d	6.5	d	d	11.8
Conduct disorder								
Ceased	d	d	9.9	d	8.4	5.4	d	d
Continued	d	d	d	d	d	d	d	24.7
Oppositional/defiant disorder								
Ceased	d	d	d	9.2	9.2	d	d	d
Continued	d	d	d	d	5.1	d	d	27.6
Attention deficit hyperactivity disorder								
Ceased	d	d	d	d	27.7	5.0	d	d
Continued	d	d	d	d	11.1	d	d	27.2
Developmental and emotional disorder of newborn and younger infants								
Ceased	d	d	d	d	5.4	12.5	d	6.9
Continued	d	d	d	d	d	d	d	47.5
Learning disorder								
Ceased	d	d	d	d	d	26.0	d	7.3
Continued	d	d	d	d	d	7.5	d	49.7
Speech and language delays								
Ceased	d	d	d	d	d	13.7	7.1	7.8
Continued	d	d	d	d	d	d	d	51.4
Borderline intellectual functioning								
Ceased	d	d	d	d	d	8.8	d	7.8
Continued	d	d	d	d	d	d	d	45.9
Schizophrenic, paranoid, and other functional psychotic disorders								
Ceased	d	d	d	d	5.2	d	d	d
Continued	d	d	d	d	d	d	d	10.1
Mental retardation ^b								
Ceased	d	d	d	d	d	7.7	d	30.1
Continued	d	d	d	d	d	d	d	81.7

(Continued)

Table 2.
Primary disability code transitions of children with mental impairments after the age-18 redetermination, 2005–2009—Continued

Child SSI recipient's primary impairment ^a	Percentage diagnosed with a redetermination impairment of—							
	Borderline intellectual functioning	Cerebral palsy	Epilepsy	Other disorders of the nervous system	Unknown, no medical evidence in file	Unknown, medical evidence insufficient to establish impairment code	Missing	Other ^c
Organic mental disorders (chronic brain syndrome)								
Ceased	13.5	d	d	d	d	5.8	7.5	16.3
Continued	d	d	d	d	d	d	d	19.9
Affective disorders								
Ceased	5.0	d	d	d	d	6.1	7.1	21.1
Continued	d	d	d	d	d	d	d	17.6
Autistic disorders and other pervasive development disorders								
Ceased	8.3	d	d	d	d	6.4	d	22.4
Continued	d	d	d	d	d	d	d	11.1
Anxiety related disorders								
Ceased	7.1	d	d	d	d	7.0	6.8	19.6
Continued	d	d	d	d	d	d	d	23.2
Personality disorders								
Ceased	7.9	d	d	d	d	6.2	7.2	21.7
Continued	d	d	d	d	d	d	d	19.3
Somatoform disorders								
Ceased	d	d	5.7	5.7	8.6	d	8.6	22.9
Continued	d	5.9	d	d	d	d	d	5.9
Eating and tic disorder								
Ceased	5.9	d	d	d	d	d	9.4	27.1
Continued	d	d	d	d	d	d	d	20.4
Conduct disorder								
Ceased	11.0	d	d	d	d	8.2	6.6	15.4
Continued	5.4	d	d	d	d	d	d	17.0
Oppositional/defiant disorder								
Ceased	9.8	d	d	d	d	7.3	7.4	20.6
Continued	5.1	d	d	d	d	d	d	17.6
Attention deficit hyperactivity disorder								
Ceased	9.4	d	d	d	d	5.5	6.4	17.3
Continued	5.4	d	d	d	d	d	d	20.2
Developmental and emotional disorder of newborn and younger infants								
Ceased	12.5	d	d	d	d	d	7.1	21.4
Continued	d	5.7	d	d	d	d	d	18.0
Learning disorder								
Ceased	16.1	d	d	d	d	d	8.2	20.0
Continued	7.6	d	d	d	d	d	d	14.2
Speech and language delays								
Ceased	18.2	d	d	d	d	5.2	7.3	24.5
Continued	6.5	d	d	d	d	d	d	26.6
Borderline intellectual functioning								
Ceased	34.4	d	d	d	d	d	8.7	19.2
Continued	16.5	d	d	d	d	d	d	18.2
Schizophrenic, paranoid, and other functional psychotic disorders								
Ceased	5.4	d	d	d	d	7.6	7.6	22.2
Continued	d	d	d	d	d	d	d	13.9
Mental retardation ^b								
Ceased	21.7	d	d	d	d	5.3	8.5	15.5
Continued	d	d	d	d	d	d	d	18.3

(Continued)

Table 2.**Primary disability code transitions of children with mental impairments after the age-18 redetermination, 2005–2009—Continued**

SOURCE: Author's calculations using SSA Office of Quality Performance CDR Waterfall File.

NOTES: Diagnoses are based on primary RPDY (Recoded Primary Impairment) codes.

Sample excludes redeterminations with an appeal decision pending and six child recipients with multiple impairment codes.

Rounded components of percentage distributions do not necessarily sum to 100.

- a. Described according to SSA listings.
 - b. SSA listings have yet to adopt the "intellectual disabilities" terminology per Rosa's Law (Public Law 111-256).
 - c. No single code within the "other" category contributes more than 5% of the total.
 - d. Between zero and 4.9%.
-

Box 1.**Recoded Primary Impairment (RPDY) codes and SSA impairment listings for childhood diagnoses arranged by the corresponding diagnostic group category used in SSA statistical publications**

Diagnostic group category and RPDY code	SSA impairment listing
Other mental disorders	
2940	Organic mental disorders (chronic brain syndrome)
2960	Affective disorders
2990	Autistic disorders and other pervasive development disorders
3000	Anxiety related disorders
3010	Personality disorders
3060	Somatoform disorders
3070	Eating and tic disorder
3120	Conduct disorder
3138	Oppositional/defiant disorder
3140	Attention deficit hyperactivity disorder
3150	Developmental and emotional disorder of newborn and younger infants
3152	Learning disorder
3153	Speech and language delays
3195	Borderline intellectual functioning
Schizophrenia, psychoses, and other neuroses	
2950	Schizophrenic, paranoid, and other functional psychotic disorders
Intellectual disabilities	
3180	Mental retardation ^a

- a. SSA listings have yet to adopt the "intellectual disabilities" terminology per Rosa's Law (Public Law 111-256).

There may be underlying societal issues at play here; as a *Boston Globe* series claims, “clinicians...often resort to using ‘speech delay’ because it is the least-stigmatizing diagnosis” (Wen 2010).¹³

Many redeterminations change recipients’ diagnoses to organic mental disorders (chronic brain syndrome), affective disorders, and borderline intellectual functioning, as well. For example, 30 percent of continued recipients and 27 percent of ceased recipients originally diagnosed with anxiety disorders are changed to the primary diagnosis code of an affective disorder. Additionally, over 20 percent of continued recipients with an original primary diagnosis code of personality disorders, eating and tic disorders, conduct disorder, oppositional/defiant disorder, and attention deficit hyperactivity disorder have their diagnosis change to affective disorder after the age-18 redetermination. Similarly, over 15 percent of ceased recipients who originally had a primary diagnosis code of personality disorders, eating and tic disorders, conduct disorders, and oppositional/defiant disorder are diagnosed with affective disorder after the age-18 redetermination.

Over one-quarter of ceased recipients initially diagnosed with schizophrenia, paranoia, or other psychotic disorder are reclassified as having an affective disorder after the age-18 redetermination, and 19 percent of continued recipients originally in this group undergo a similar change. Twenty-two percent of ceased recipients originally diagnosed with an intellectual disability are reclassified as having borderline intellectual functioning. Those results may appear odd, as those disabilities are typically considered lifelong conditions; however, SSA considers intellectual disabilities to be dynamic, especially before age 16 (SSA 2012c). Also, recall that this study only observes the primary diagnosis. Some changes may simply reflect reorganizing the codes into the most prominent or best-documented disabling condition; likewise, the original disabilities may be recorded as secondary codes or in some other way not observable from the record.

At least as of the initial redetermination decision, 6 percent of continued recipients with schizophrenia, paranoia, or other psychotic disorders and 5 percent of those with intellectual disabilities retain their primary youth diagnosis (not shown). This change from primary to secondary disorder is more common for “other mental impairment” diagnosis codes, applying to almost 20 percent of continued recipients originally diagnosed with anxiety related disorders, 17 percent of those with affective disorders, and 15 percent of those with either personality disorders or autistic disorders and other pervasive development disorders.

There are two other findings of note. First, relatively few ceased recipients with mental impairments have either no medical evidence on file or insufficient evidence to establish an impairment. For over 90 percent of almost all diagnosis codes, the cessation decision was based on an impairment.¹⁴ Second, both continued and ceased recipients with mental impairments change to a wide range of primary impairments. The average number of new individual post-redetermination primary diagnosis codes for each pre-redetermination diagnosis code is 28 for continued recipients and 33 for ceased cases (not shown in Table 2).

¹³ For a closer look, I examined the highest secondary impairment code available in the data extract used in this study (either the initial decision or reconsideration decision at the Disability Determination Service). Among continued recipients whose primary impairment changed from “other mental disorders” to intellectual disability upon redetermination, roughly 16 percent retained their original classification as a secondary diagnosis, at least at the initial redetermination decision level. That outcome was most common among youth with autistic disorders and other pervasive developmental disorders (45 percent) and with affective disorders (42 percent). The initial redetermination matched the final decision for roughly 87 percent of youth in the sample.

¹⁴ It may be argued that the examiner simply records the original disability; however, the number of changes in codes suggests otherwise.

Concluding Remarks

This note provides information on the changes in the diagnoses of disabled youth SSI recipients resulting from age-18 redeterminations, using the primary diagnostic groups SSA uses in its statistical publications. Although less than one-half of youth retain the same diagnosis after their age-18 redetermination, two-thirds remain in the same diagnostic group. Many of the changes are from the “other mental disorders” group to the “intellectual disability” group or within the “other mental disorders” category.

Further research is necessary to determine if the redetermination diagnoses were always present or if the change represents a different diagnosis of the same symptoms or underlying disability; however, at least at the initial redetermination decision level, the primary and secondary diagnoses exhibit some interchange. Also unclear is whether the timing of the original diagnosis affects changes in primary impairment. It is possible, for instance, that diagnoses made before entering school, or after several years in the educational system, may be less prone to change than those made upon first entering school. Future research can also explore how recent societal trends in the use of certain diagnoses—for example, away from intellectual disabilities and towards autism spectrum and related disorders—have impacted the age-18 redetermination decision and SSI population statistics. Such research would include the effects of changes to the Diagnostic and Statistical Manual of Mental Disorders (DSM) on the overall prevalence of mental disabilities.

Analysts have given much attention to the recent growth of the child SSI population with certain impairments, such as attention deficit hyperactivity disorder and learning disabilities. Indeed, many of these impairments have much lower-than-average continuation rates—youth recipients diagnosed with attention deficit hyperactivity disorder and borderline intellectual functioning, in particular, are the most likely to cease. However, these statistics do not provide a complete picture; the duration of some of these mental disorders may be related to the social and intellectual maturation of the child. Further research should consider the changing impact of these disabilities over the life course on an individual’s functional development. Just because SSI payments cease in adulthood does not mean that the former recipient did not have a qualifying condition during his or her youth.

Appendix

Table A-1.
Age-18 redetermination outcomes by year of release

Year	Number of initial decisions	Percentage distribution of outcomes		
		Continuations	Cessations with no appeal pending	Cessations pending an appeal decision ^a
Total	340,762	57.8	34.6	7.7
2005	64,573	62.4	36.9	0.7
2006	69,851	59.5	38.4	2.1
2007	74,633	57.9	36.3	5.8
2008	76,137	55.5	30.9	13.6
2009	55,568	53.2	29.7	17.1

SOURCE: Author’s calculations using SSA Office of Quality Performance CDR Waterfall File.

NOTE: Rounded components of percentage distributions do not necessarily sum to 100.

a. Not included in the analysis.

References

- Burkhauser, Richard V., and Mary C. Daly. 2011. *The Declining Work and Welfare of People with Disabilities: What Went Wrong and a Strategy for Change*. Washington, DC: AEI Press.
- [GAO] Government Accountability Office. 2011. "Supplemental Security Income: Preliminary Observations on Children with Mental Impairments. Statement of Daniel Bertoni, Director, Education, Workforce, and Income Security." Testimony before the Subcommittee on Human Resources, Committee on Ways and Means, House of Representatives, No. GAO-12-196T.
- Hemmeter, Jeffrey, and Elaine Gilby. 2009. "The Age-18 Redetermination and Postredetermination Participation in SSI." *Social Security Bulletin* 69(4): 1–25.
- Hemmeter, Jeffrey, Jacqueline Kauff, and David Wittenburg. 2009. "Changing Circumstances: Experiences of Child SSI Recipients before and after Their Age-18 Redetermination for Adult Benefits." *Journal of Vocational Rehabilitation* 30(3): 201–221.
- Panis, Constantijn, Roald Euler, Cynthia Grant, Melissa Bradley, Christine E. Peterson, Randall Hirscher, and Paul Steinberg. 2000. *SSA Program Data User's Manual*. PM-973-SSA. Santa Monica, CA: RAND Corporation.
- Rogowski, Jeannette, Lynn Karoly, Jacob Klerman, Moira Inkelas, Melissa Rowe, and Randall Hirscher. 2002. *Final Report for Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children*. DRU-2559-SSA. Santa Monica, CA: RAND Corporation.
- [SSA] Social Security Administration. 2012a. *Annual Report of Continuing Disability Reviews. Social Security Administration, Fiscal Year 2010*. Baltimore, MD: Social Security Administration, Office of the Chief Actuary.
- . 2012b. "Program Operations Manual System (POMS) Section DI 26510.015: Completing Item 16A and 16B (Primary and Secondary Diagnosis, Body System Code and Impairment Code) on the SSA-831." <https://secure.ssa.gov/apps10/poms.nsf/lrx/0426510015>.
- . 2012c. "Program Operations Manual System (POMS) Section DI 24515.055: Evaluation of Specific Issues Psychological/Psychometric Testing." <https://secure.ssa.gov/apps10/poms.nsf/lrx/0424515055>.
- Wen, Patricia. 2010. "The Other Welfare: A Coveted Benefit, A Failure to Follow Up." *Boston Globe*, December 13. http://www.boston.com/news/health/articles/2010/12/13/follow_up_process_lacking_in_ssi_disability_program/.